## **RESPONSE**

# NICE is not cost effective

### **J Harris**

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laxton and Culyer¹ (see *p* 373) have written an interesting and considered response, as people intimately connected to the National Institute for Health and Clinical Excellence (NICE), to the two editorials that I wrote on recent NICE decisions. Before commenting on their response, I would like to consider a point they made, which echoes a point already made by Rawlins and Dillon,² about the tone of my editorials. Claxton and Culyer accuse me of making "personally abusive charges". In my original editorial, I criticised an institution, NICE, in robust terms, but in doing so I was continuing a long and respected tradition in English philosophy. Consider the following extract from Jeremy Bentham:

In English law, fiction is a syphilis, which runs in every vein, and carries into every part of the system the principle of rottenness ... Fiction of use to justice? Exactly as swindling is to trade...It affords presumptive and conclusive evidence of moral turpitude in those by whom it was invented and first employed.<sup>3</sup>

My remarks were not an ad hominem criticism of anyone but directed at the published, but anonymous statements of an institution—a body corporate. In robustly criticising NICE, I no more attacked any individual associated with NICE than I attacked Tony Blair or the various ministers of state who are ultimately responsible for NICE. And, contra Claxton and Culyer's claims, I have not denigrated the views of people who beg to differ from me.<sup>i</sup> If the apologists for NICE, whether they are Tony Culyer or Tony Blair, choose to identify themselves with criticism of NICE, that is entirely a matter for them. The only ad hominem remarks in this entire exchange have been made by Rawlins and Dillon, and Claxton and Culyer. The idea that criticism of the anonymously authored publications of a body corporate could be "personally abusive" is absurd.

In this brief rejoinder I will make just main two points.

### **MEANING OF COST EFFECTIVENESS**

The first point concerns the meaning of cost effectiveness, but I must admit to an error that I made in my editorial. Claxton and Culyer say I suggest that the provisional recommendation to reject Alzheimer's drugs will "have very bad consequences for thousands of patients and good consequences for none". I did suggest this because it is impossible to know what, if any, good consequences they have. I should have said "denial of the drugs will have very bad consequences for thousands of patients and it is unknown whether it will have good consequences for any"—that is, it is unknown whether the decision will secure any benefits large enough to justify such costs.

For the record, I have never claimed that health benefits to be gained from treatment cannot or should not be balanced against the health gains that must be sacrificed to secure such benefits. The disagreement is over what is to count as a health benefit and about whether NICE makes or has any basis for the calculations, which alone could justify their policy.

Claxton and Culyer are surely right when they analyse what it means to say a procedure is not cost effective in the following terms that:

In the context of NICE and the NHS this means that the health benefits that it is estimated can be gained from the technology are less than those estimated to be forgone by other patients as other procedures are necessarily curtailed or not undertaken. It is this comparison of health gained and health forgone that is at the heart of the rationale of cost-effectiveness analysis and the debate between Harris and the senior officers of NICE.

I agree that this is precisely the heart of the matter and of my criticisms of Dillon and Rawlins, and now of Claxton and Culyer. If "the health benefits that it is estimated could be gained from the technology are less than those estimated to be forgone by other patients", NICE's decisions may at least be coherent in their own terms. But we are now told that such estimates were not and could not be made. Claxton and Culyer admit that "NICE does not and cannot evaluate all possible uses of healthcare resources at any one time and generally cannot know which NHS activities will be displaced or which groups of patients will have to forgo health benefits. Harris is certainly correct about this. But what may be inferred from this? Again it is not clear what he is arguing."

Let me then be very clear about what I am arguing. What may be inferred (and indeed is explicitly now admitted) is that NICE cannot, and in fact, does not make cost-effectiveness assessments of the procedures it recommends as cost effective or indeed condemns as not cost effective. In short, NICE simply does not and cannot know what it is doing. NICE does not know what, if any, benefits will be foregone by other patients when it refuses to approve a procedure and therefore lacks, on Claxton and Culyer's own analysis, the comparison that is "at the heart of the rationale of cost-effectiveness analysis".

Let this be crystal clear. Claxton and Culyer are saying that it can be said that a procedure is cost effective if and only if "the health benefits that it is estimated could be gained from the technology are less than those estimated to be forgone".

iClaxton and Culyer say "the editorials are littered with other personally abusive charges, including one of hypocrisy". Such charges I make against NICE may be personally abusive if they were directed at any individually identified person. I was using "hypocrisy" according to the definition in The shorter Oxford English Dictionary,4 to mean "the assuming of a false appearance of virtue or goodness" by NICE in its published, but not individually authored, material. I do not think that to say of a corporation that its stance is "assuming a false appearance of virtue or goodness" and to explicitly state why this appearance is false could be called "abusive", let alone "personally abusive". I stand by this charge against NICE. The reasons that justify the use of the term "hypocrisy" against this corporate body, but against no individuals, are clearly set out in my editorial.

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At the same time, they make it clear that no estimate is or can be made by NICE of the benefits to be foregone! What may be inferred and what is now actually admitted is that NICE, in the expert opinion of Claxton and Culyer, cannot and is not making its decisions on the basis of cost-effectiveness analysis as Claxton and Culyer themselves define it. Moreover, the claim that can alone justify NICE's decisions "that the health benefits that it is estimated could be gained from the technology are less than those estimated to be foregone by other patients" cannot be sustained! This is a staggering admission of the correctness of my criticism of NICE and discloses a fatal flaw in the methods and procedures of NICE.

If it is true, as Claxton and Culyer now claim, that it "is this comparison of health gained and health forgone that is at the heart of the rationale of cost-effectiveness analysis", then if NICE accepts the Claxton and Culyer analysis, NICE cannot plausibly claim that its decisions are based on the cost effectiveness of the various procedures it considers.

The bottom line is that it is unethical to claim that a treatment is not cost effective and on this basis to deny treatment to patients who would clearly benefit from it and then to admit that the comparisons necessary to sustain the claim on cost effectiveness, which supposedly constitute the moral justification for the decision, have not and cannot be made.

The second fundamental point of disagreement between Claxton and Culyer and myself concerns what counts as a health benefit.

#### **VALUE OF LIFE**

After rehearsing several possible views that Claxton and Culyer think I may hold but which I decidedly do not, they do identify a point on which we actually disagree. They defend the interpretation of quality-adjusted life years (QALYs) that I have identified as "vicious" (which term, for the record, I am using and have consistently used in the very first sense identified by the *Oxford English Dictionary*, namely "of the nature of vice; contrary to moral principles".<sup>4</sup>

Claxton and Culver say:

What Harris may be really objecting to is the idea of taking any account at all in assessing health gain of the amount of future time spent in whatever state it is spent in. It is plainly possible to hold the view that five years of future life of a given quality is to be valued the same as a week of life lived at that quality or 50 years lived at that quality. The prevailing view seems to us, however, to have been that people not only prefer good quality life to poor quality life but also more life of a given quality to less ....

Claxton and Culyer seem to subscribe to a sort of populist test of ethics, which holds that what people want or would agree to is what is morally right. They are, however, playing fast and loose with the idea of what constitutes evidence for what people want.

Of course people "prefer good quality life to poor quality life but also more life of a given quality to less" when choosing between possibilities for themselves. That does not mean, however, that they would have these preferences when the benefits are to be experienced by others, nor does it follow that this personal preference commits them in logic to such a policy! In my second editorial I gave an example that illustrated this

point and showed the fallacy not only of the reasoning that Claxton and Culyer deploy, but also the one at the heart of NICE's claim to public endorsement for its strategy.

Imagine twin sisters, Jackie was born paralysed from the waist down and Jill was born healthy. Now in their thirties, Jackie has established a life for herself that she finds worthwhile and satisfying. So has her twin. Both agree, however, that Jackie's quality of life is objectively substantially lower and both agree that Jackie's life expectancy is substantially the lesser. Both, we will suppose are now involved in an accident and resources available can only treat one before death strikes them both. ... it seems to me that not only is it unethical to choose between them .... There is no rational basis for so doing. Both want to live, both have lives they find worthwhile.

In this case, both sisters agree that if they had the choice they would prefer Jill's life to Jackie's. It does not follow that both of them are committed to the view that health resources should be devoted to Jill rather than to Jackie. When Claxton and Culyer say "people not only prefer good quality life to poor quality life but also more life of a given quality to less" they are right, but they imply that this means that if NICE implements policies that condemn Jackie to death and rescue Jill this somehow has the endorsement of both sisters and of all those who want longer and healthier lives!

The flaw at the heart of the QALYs that Claxton and Culver endorse is easily seen. The whole plausibility of QALYs depends on our accepting that they simply entail the generalisation of the "truth" that "given the choice a person would prefer a shorter healthier life to a longer period of survival in a state of severe discomfort". Therefore, giving priority to treatments that produce more QALYs or for which the cost per QALY is low is both efficient and also what the community as a whole, and those at risk in particular, actually want. Whereas it follows that given the choice, a person would prefer a shorter healthier life to a longer one of severe discomfort, that the best treatment for that person is the one yielding the most QALYs, it does not follow that treatments yielding more QALYs are preferable to those yielding fewer when different people are to receive the treatments.

I maintain, contra the QALY assumptions, that the value of life and hence the value, the moral importance, of saving a life is not proportional to the length of the life or the life expectancy of the person whose life it is. It follows that life years to be gained from treatment are irrelevant when different people are to receive the treatment.

If you hear that a hundred innocent people have been murdered, the offence would hardly be mitigated if it emerged that the victims were all old people, or children, or severely ill, hospitalised patients. Suppose the same hundred people were in need of medical treatment, what would lessen our sense of the moral importance of saving their lives?<sup>5</sup>

This is the point so well made by Mars Jones, which I quoted in my editorials and which is signally misunderstood by Rawlins and Dillon and no less than by Claxton and Culyer:

However gravely ill a man may be ... he is entitled in our law to every hour .... that God has granted him. That hour or hours may be the most precious and important hours of a man's life. There may be business to transact, gifts to be given, forgiveness to be made, 101 bits of unfinished business, which have to be concluded.

<sup>&</sup>lt;sup>ii</sup>Contra what Claxton and Culyer seem to believe, this point has nothing to do with whether those who have to forgo benefits are personally identifiable or not.

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Mars Jones's point is precisely the one I am making and it is one shared by English law and even by common sense. The size of a disaster is measured by the lives lost, not by the life years lost. English citizens are (contra NICE) entitled to have "their lives" valued by the NHS, not simply their "life years"

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